

COMMUNICATING TOGETHER

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EDITORIAL

SHIRLEY MCNAUGHTON

PETER LINDSAY



Did you notice the change in the Table of Contents this issue? Five *Readers Writing!* We welcome their contributions and the thinking they stimulate and we have given them priority over *SymbolTalk* for this issue. We will comment later in our editorial on what seems to be happening as **Communicating Together** provides a forum for the differing perspectives of those involved in AAC.

Empowerment and Advocacy were selected by our editorial team as topics for the theme of this issue because of their critical importance for AAC users. During a period of economic restraint, the needs of those not well placed on the political ladder are all too often pushed downward. A focus upon both empowerment of the individuals concerned and advocacy on their behalf is needed if the rungs of the ladder are to be strengthened and climbed!

We begin by looking back to remind ourselves of our expectations as we entered the nineties. Sarah Blackstone expressed the sentiments of many persons attending the Visions Conference, sponsored by the Applied Science and Engineering Laboratories, University of Delaware and the Alfred I. duPont Institute in February, 1990 when she commented:

AAC in the 1990s will begin to be led by consumers. To date, the way has been paved almost exclusively by manufacturers, clinicians, and a few resourceful parents/spouses. In general, we've done "okay" but get ready to hear about our oversights/mind-sets/blind spots!

Blackstone, 1990.

Visions Conference Presentations, p.1

Well, the time has come for recognizing and dealing with those oversights/mind-sets/blind spots! Several of the articles in this issue help us do just that. In *Teaching and Learning*, Nola Millin tells us about the role of decision-making in empowerment. Paul Marshall reflects upon *empowerment from within* in *Paul's Place*. Kari and Ruth Harrington, in *Living*, describe the risk-taking necessary for an AAC user to move toward independence. In *Consuming Technology* Robert Haaf urges clinicians to take an active role in supporting the growing empowerment of AAC users and in so doing empower themselves in the true sense of their service role. Geb Verburg, in *Contexts*, calls for a new professionalism, one that recognizes the right of choice for individuals who use AAC. Lucy Costa Nyman, Youth Advocacy Network Coordinator with Persons United for Self Help (PUSH) - Ontario, points out the unique and challenging position within the disability field of people who use AAC and describes a Toronto conference planned by and for AAC users. Please note our cover picture in which Lucy is involved in one of the conference's discussion groups. Observe the mix of speaking persons and AAC users - a balance we would always hope for as we work together toward empowerment for AAC users!

Given that the theme of this issue is *Empowerment and Advocacy*, we could not help but reflect on the content being fifty percent related to facilitated communication (FC). Why is the field of AAC giving such a large amount of attention to FC? Why are we devoting so much space to this one topic within **Communicating Together**? How does FC relate to empowerment and advocacy?

Learning from the FC Train

Facilitated Communication seems to be offering us an enlarged picture of a phenomenon that occurs frequently within AAC. A technique or approach meets success with a few individuals, within a well supported program or one with exceptional instructors. Word gets around. Others attempt to replicate the results clinically or educationally. Some succeed. There is a demand for training. Large numbers of professionals are minimally trained, become committed and enthusiastically apply the technique to *everyone* in their program or school. For a few individuals, the technique may be appropriate; for many others, it may not. Research studies are undertaken, but clinicians and families feel they've missed the mark. The gap between the technique supporters and its critics widens. Many AAC users are affected negatively. The field moves on to a new focus, leaving many issues unresolved.

We hope our field can learn to do much better than this in many areas, but particularly regarding FC where so much can be at stake. Stephen Calculator and Beverly Vicker, through well considered articles in this issue, call for caution and common sense. Sound advice! Rosemary Crossley's concern regarding the interpretation of the

current research findings challenges us to look carefully at the clinical reports and studies to date and to press for more varied types of validation.

The various positions coming forth with regard to FC should serve as a reminder to all of us of the caution that is needed in all areas of AAC. We really do have a lot still to learn! And we need the help of AAC users at all levels of discussion. *We* need their empowerment! We have a long way to travel together before being able to realize our goal of communication competence for all persons with communication impairments.

Perhaps our preoccupation with FC will provide us with some of the questions that cry out for answers. The powerful impact it can have, for both harm and good, makes it imperative that we respond quickly. How can we work toward the empowerment of individuals if we make them forever dependent upon facilitation? (Perhaps another look should be taken at Rosemary Crossley's preference for Facilitated Communication *Training*!) How can we ensure in any situation, facilitated or otherwise, that we speaking individuals are not controlling the communication of the AAC user? How can we responsibly provide information and support that will nurture empowerment? And, there is an important lesson about advocacy to be gained from the rapid growth and sometimes inappropriate application of FC. We must ensure that our advocacy is constructive, that our efforts are leading to better programs *for the particular individuals* we are attempting to help! We must be able to look to research to help us!

Another area for learning

We have attempted through **Communicating Together** to provide a meeting place for individuals who use AAC and those who work in the field as clinicians and researchers. Through some of the papers and letters submitted for this issue, however, we have been struck with how stressful this

exchange of views can be. In Anne McDonald's response to Howard Shane's article from the June **Communicating Together**, and Ruth Sienkiewicz-Mercer's and Rick Hoyt's reaction to Anne McDonald's letter, the misunderstandings that can arise when two very different worlds meet become disappointingly evident.

Howard Shane's June article was based on the empirical evidence of his own and other published research and on his extensive clinical experience. He took a strong position as evidenced in his title, *FC: Facilitated or 'Factitious' Communication*. He was reacting to the many instances he had witnessed of Facilitated Communication leading to wrongful allegations of sexual abuse, inadequate educational placements and inappropriate communication recommendations. The "runaway train" that we wrote about in our December, 1992 editorial has been causing serious harm to many individuals. Howard Shane used a scientific approach - quantitative research - to attempt to stop the train.

Anne McDonald reacted to Shane's article as an individual feeling personally attacked. How easily this can happen! After all, she credits her own communication competency to facilitation. Anne accuses Howard Shane of "writing off people who cannot talk". And equally understandably, two AAC users who have been helped greatly by Shane have risen to his defence. His many years of work on behalf of those who are nonspeaking can be well attested to by both Ruth Sienkiewicz-Mercer and Rick Hoyt, and by many others in the AAC field.

So, what can we do about an AAC user feeling personally belittled and others feeling the need to defend a highly respected professional? We are concerned that through the interaction of two

domains — the personal and the scientific — the nature of the dialogue has gone awry. It is interesting that Rick Hoyt, an AAC user, identifies the problem!

We are onto sensitive new ground, as consumers take their rightful, more active role in our field. Those of us who have a professional role do indeed need to be on the lookout for our oversights/mind-sets/blind spots. As we engage in our scientific discussions, we need to clarify the limits and present the rules of scientific enquiry. If the research is quantitative, like Shane's, we should ask questions related to the study's design. We should remember that researchers can never prove that something *doesn't* exist, only that they currently lack evidence that it *does* exist. They can never say never! So, we must understand, when Howard Shane writes, "By all scientifically based indications, Facilitated Communication does not work", he is commenting that in his opinion FC has not been adequately demonstrated in a controlled *scientific* experiment. Supportive or counter arguments to his position must be presented through reference to other research findings. Rosemary Crossley takes on this task in her letter appearing on page 19.

Consumers must be on guard as well, against *their* oversights/mind-sets/blind spots. Results from scientific studies pertain to subjects within controlled and limited situations. No personal slight should be taken as the results pertaining to a group of subjects within a particular research study are presented, interpreted and debated. As consumers enter the scientific arena, we all need to refine our communication and our knowledge of the discourse rules. We will all be the richer!

Next issue

The March 1994 issue will be coordinated by Nola Millin and will be by and about AAC users. The topic will be *Who Am I? How I See Myself as an AAC User*.

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Advocating for Yourself

LUCY COSTA NYMAN



Lucy Costa Nyman is the Youth Advocacy Network Coordinator with Persons United for Self Help (PUSH) - Ontario. She works on behalf of young people with all types of disabilities.

I have been working at PUSH - Ontario, advocating for the rights of people with disabilities, for three years. Recently I was part of a panel discussion at the first conference for people who use Bliss and other Augmentative and Alternative Communication systems (AAC). The conference brought together people with disabilities who use AAC, services providers and family members to discuss the future of this community. It was exciting for me to see people who belong in my community but are often left out, advocating for themselves. It was also encouraging to watch service providers facilitate the process of communication in such a way that people who use AAC could create their own voices and "speak" for themselves.

People with disabilities who use AAC rarely have an opportunity to say what they would like to do with their lives, are often not listened to, and rarely have complete control over their own lives. It is a common problem that people who are involved in the lives of adults who use AAC, try to speak for and take

decision-making rights away from AAC users. Or they simply blunder ahead and do not bother to ask individuals to repeat themselves when they do not understand what it is they are saying and *deciding*. Communicating and making decisions for one's self is a basic right. I don't know many people who would be willing to sit back and let someone else speak or make decisions on their behalf. So why does the community at large assume that it's O.K. to speak for people who use AAC?

Communication is very personal and powerful. It is our way as individuals to express how we feel, what we would like to do with our lives and who we are. It is the basis of all relationships. People who use various forms of AAC, want their right to be heard as well as their right to make decisions for themselves. This conference created an opportunity for people who use AAC to start taking greater control over their own lives.

The panel in the morning was comprised of people who use AAC, one family member and myself. We focused on questions about how people who use AAC feel about themselves, if they thought that their community takes the time to understand their method of communication, and if people who use AAC are getting the assistance and technology they need to achieve their right to communication and to make independent decisions.

Throughout the remainder of the day, the conference participants brainstormed different ways of advocating for their issues. They discussed directions they would like to see AAC systems go in the following areas: the school system, high tech applications, assisting young children to get started with

AAC, and assisting adults users of AAC to advocate for themselves.

There were four discussion groups in the afternoon. They focused on the following questions which had been developed by the program organizers, Paul Marshall, John Dowling and Nola Millin:

- 1) Is the school system addressing the needs of or giving the right skills to young people who are AAC users?
- 2) Do parents need more support around AAC issues?
- 3) Do care-givers need more basic teaching around AAC issues?
- 4) Should people who use AAC be doing more general public awareness work?
- 5) What role do people who use AAC see themselves playing in promoting its use?
- 6) What role do people who use AAC see themselves playing in advocating for their rights?

At the end of the day, the outcome was that those present decided to work toward AAC users assuming greater control and direction over their lives. A task force was established - to examine the issues raised during the day and develop a concrete action plan. Paul Marshall and Nola Millin agreed to co-chair the task force. An important mandate given to the task force was to develop the ways by which conference participants could contribute to the empowerment of young people and children who are and will be using AAC systems. This is of course how it should be. After all AAC consumers are the real "experts" on AAC systems.

Empowerment Through Risk-taking

KARI & RUTH HARRINGTON

This time, Ruth wrote the first draft. Kari had the final say as usual!

Last spring Kathy Pahl, a member of the Recreational Staff at Participation House, Markham, wrote a paper entitled "*Parenting and the Right to Risk Among People with Developmental Disabilities*" for a course she was taking. Kathy confined her paper to the consideration of the influence of parenting on the 'right to risk' among people labelled mildly to moderately developmentally disabled including those who have physical disabilities. She limited the scope of her paper to individuals who were raised to adulthood within the family.

Aside from considerable reading on the subject, Kathy asked Kari to write down her feelings on risk-taking and personal empowerment while she was growing up. Kathy also included the story of Kevin and his family, whom Kathy had known for a number of years through their involvement with Participation House.

When Kari knew this issue of **Communicating Together** was to focus on empowerment, Kathy's paper popped into her mind right away. Kari asked Kathy if we might borrow her paper, use some of the information in it, and, with Kevin's permission, tell his story as Kathy had written it. Kevin and Kari have been friends for many years. They know each other's differences and experiences very well and can see for themselves the effect these differences have had on taking control of their own lives.

Before beginning Kevin's story, we would like to include some of the information Kathy presented in her paper, facts which Kevin's mother and father must have instinctively known when raising their son.

Empowerment is a long process. The goal of empowerment is to achieve the greatest possible control over one's own life by being allowed to make the decisions that affect its quality. By definition, risk-taking involves the potential for making mistakes. The opportunity to make mistakes is one of the basic rights of being human and the only way by which to discover one's own abilities and limitations. The very activities of daily living and the decision-making associated with these activities, involve elements of risk for everyone. However, controversy and fear more often surround the issue of 'the right to risk' when it is applied to someone labelled cognitively and/or physically disabled. Because of the widely variant degree of cognitive or physical limitation identified by these labels, decisions about what is 'reasonable risk' must be made on an individual basis. What is required is good, sensible and least restrictive support of family, friends, community and people working with the individual. Ideally, the degree to which reasonable risk might be judiciously taken is assessed functionally with the disabled person, by supporting them in decisions, and giving them appropriate preparation and opportunities for learning, including high, growth-promoting expectancies of their personal ability.

It is said that the difficulties related with becoming empowered increase proportionately with the amount of time one spends in a state of disempowerment. This fact and the principles of normalization substantiate the importance of early parental encouragement and promotion of risk-taking so that the individual develops an ability to judge and foresee

consequences through the experience of cause and effect. Empowerment begins at home, with parental support of the disabled person's early experiences of exploration, cause and effect and natural consequences, towards the discovery by the individual of her/his own capabilities and limitations.

Unpublished paper, Katherine Pahl, 1993

Kevin's Story

Kevin is a 29-year-old man with cerebral palsy who has some speech impairment and a rather high degree of spasticity which affects his ambulation and the fine motor use of his hands, and intensifies his startle reflexes. He walks with an unsteady gait and uses an adult tricycle for much of his mobility.

From early on, Kevin demonstrated a determination to pursue whatever activities he wished. He seldom permitted the possibility of failure due to his disabilities to prevent him from trying something. Ice skating and driving a car are two examples. Despite his parents' certainty that they were beyond his capacity, they supported his endeavours. It was his own experience in trying both these activities rather than the advice and admonitions of others that taught Kevin that ice skating and driving a car were not possible for him. His high expectations and self-confidence were nurtured within the family. Their enthusiasm as he initiated new activities and faced difficult challenges allowed Kevin to assume control over decisions affecting the quality of his life.

Kevin grew up within sight of the local elementary school. His parents had been assured by the principal and teachers that every effort would be made to meet his needs there. His rehabilitation doctor at the time, however, insisted that it would be far too dangerous for Kevin to be

exposed to the jostling of the other students in the halls and school yard and firmly recommended that Kevin attend a segregated school for physically disabled students. After his first day there, Kevin returned home cut and bruised. It was difficult for him to keep out of the way of those sometimes unpredictable electric wheelchairs and even the crutches. Kevin remained in the segregated setting for several years before moving to a community school for his intermediate education. His move at that time was a successful one. Could he have accommodated to this integrated setting earlier? Could those many hours on the bus have been put to better use? The experience of walking to the neighbourhood school, with all *its* possible risks, might have been preferable to spending three hours a day staring out the window

of a bus to get to this special school. There could have been an enhanced sense of safety because the neighbourhood was accustomed to seeing Kevin out and about. He was known and 'belonged' as part of the community.

There have been many times during Kevin's frequent adventures in independence when his risk-taking has taken a dangerous turn and he has been helped by a local child or parent. The natural occurrence of being given a hand by another kid, rather than always being rescued by his mom and dad has provided Kevin with a sense of normal safety in his own neighbourhood. Through real experiences, he has been given the opportunity to discover his own abilities and limitations. He has been allowed to take risks and learned what is *reasonable* to attempt in his own community.

A little over a year ago, Kevin made a successful transition from home to his own apartment where he receives the support services he must have and the freedom he wants to make his own choices about *his* path through life. Empowerment can come through many different routes. For Kevin, it came primarily through the risk-taking of integration. For others, the long process of discovering one's own abilities and limitations through being able to make mistakes may need the specialized support services of a segregated setting. We have often compared Kari's growing empowerment with Kevin's and know that support to decision-making, preparation and opportunities for learning, and growth-promoting expectancies of personal ability can come in many forms and in many different settings.

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**Congratulations to
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AICA is a charitable organization in Milan, Italy, focusing its service upon those with speech impairments and providing a strong and highly publicized focus upon AAC. In choosing AICA as the winner of the 1993 award, recognition is given to AICA and to the many other organizations in Italy and elsewhere in Europe who are providing exemplary communication service to AAC users. AICA serves as an excellent model for the attention it has given to high quality materials and the extensive effort it has directed toward the dissemination of many types of information to attract the community's interest in AAC. In addition to its service, training, public relations and fund-raising activities, AICA has a Scientific Committee for scientific research and has hosted an Italian Symposium on AAC (1990) and an International Symposium on "Natural and Artificial Systems of Human Communication" in 1992.

The award will be presented by Shirley McNaughton in Maastricht at ISAAC '94, the Sixth Biennial Conference of the International Society for Augmentative and Alternative Communication (ISAAC),

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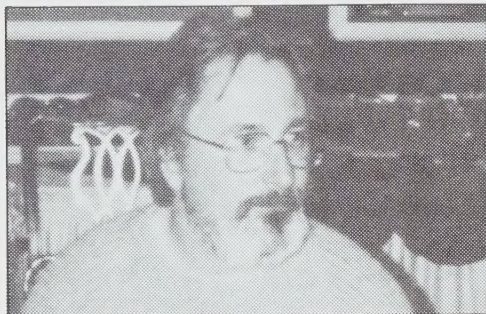
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Supporting the Empowerment of AAC Users

ROBERT HAAF



In considering the notions of “advocacy” and “empowerment” for this issue, I came to realize that I must finally make a confession that may identify me for all time as politically incorrect: I continue to resist the use of the word “consumer” in my day-to-day dealings with AAC users, families and others. I agree that the term may serve to identify the user of AAC aids and devices as the final decision-maker. It highlights the fact that the AAC user must take the initiative in controlling service provision. It also implies a relationship within our culture however that is somewhat adversarial: ‘Buyer beware’. Surely this is not the most appropriate relationship between a client and a clinician.

It is certainly part of my job to be knowledgeable about the variety of communication devices and options available, and to present these options to my clients. However, I like to think that I can help guide clients through the array of choices and decisions based on *their needs*, rather than any need of my own to provide a certain device. If the client’s needs are to be effectively met, the client/clinician relationship must be one of two-way education, mutual decision-making and respect for each others’ specific knowledge and point of view. The process is cooperative, ongoing, and not simply a case of one individual enlisting the services of another. I

value this aspect of my client relationships very highly. This however is definitely *not* how we typically define the relationship of consumer-service provider in our society. As such, I think the label of ‘consumer’, while striving to define the need for client empowerment and control, often does the actual relationship a disservice. Additionally, I think the “consumer model” may reflect a trend in the field of AAC service provision that I find disturbing: The role of the clinician is simply to provide the device, not the information and ongoing support that will ensure the device can be used effectively.

If, as Nola Millin states elsewhere in this issue, ‘advocacy’ is “standing up for your rights or the rights of someone else”, and ‘empowerment’ is the “state of being given the necessary facts to make a decision”, I could better define my role as an advocate who supports the needs of AAC users, until such a time as they are empowered with the information to become their *own* advocates. I don’t expect clients who are entering the device provision system for the first time to come already knowledgeable about the options available. They come knowing their own communication needs and desires and the AAC clinicians should have the specific knowledge to help them make a decision. Ideally through this process, the client will gain enough information to become a self-advocate. The process is ongoing, and the movement is toward transferring control to the client. If ‘empowerment’ as I’ve defined it here is the goal of the clinician, then the role and rights of the AAC user are respected.

Having said this, however, I do feel that at a certain level in the hierarchy of providing communication devices, the notion of “consumer” starts to become more valid. From the standpoint of those who design and

manufacture communication devices, both the user *and* the professional are potential “consumers”. After all, device manufacturers and developers *do* have the economic motivation to produce devices that effectively meet existing communication needs, and to promote those devices over others available. Therefore, manufacturers need to be responsive to the feedback from *all* of their consumers, in order to improve their products and to keep them competitive.

Since individuals who need AAC devices routinely turn to clinicians for advice, training, support and funding assistance, manufacturers certainly recognize the need to convince professionals that their product will best meet the needs of some clients. It is clear that the professional consumer has well-established lines of communication with the manufacturers: We get an opportunity to view new developments at conferences, training workshops, at other professional meetings as well as in our own work environments.

While the “professional consumer” is usually well served by device suppliers, it is not clear to me that those who *use* AAC devices have such clear and direct lines of communication to those who develop the devices. It’s been my experience however that clients and families often develop impressive knowledge of the strengths and weaknesses of their own communication system once it is in place. This knowledge is typically relayed to the clinician, who may (or may not) inform developers and others through one of the channels I’ve mentioned. My question is: Why? Shouldn’t clients who are knowledgeable about their systems be the ones to share that information not only with clinicians, but with developers and other AAC users? A dependency on the clinician is maintained as long as he or she acts

as an information conduit for clients who should themselves be empowered to seek out and impart information directly. This dependency puts an ultimate limit on how self-reliant an AAC technology user can become.

There is no doubt that many new communication devices (and new features for existing devices) have appeared in recent years. Equally exciting new technology is being planned and introduced as I write this. However marvellous and useful many of these innovations may ultimately turn out to be, I can't help but wonder how consistently the potential users are involved in device planning and design, and how often AAC users can provide *direct* feedback to manufacturers and developers to continually improve and refine the process.

To try and answer this question, I spoke with representatives of developers and manufacturers of AAC devices. My questions were simple: What new developments in technology are being planned? What steps are taken within your organization to involve consumers in the planning of these developments? What feedback channels exist for the users of these devices to communicate *directly* with developers and manufacturers?

The responses from the *Prentke Romich Company (PRC)* are typical of what I found. Barry Romich stated that "technology doesn't drive what we do...we're driven by consumer needs, and the language (development) issues around improving our products."

An example of new technology developments at the PRC is the AlphaTalker™. Based directly on consumer request, both users and clinicians, the AlphaTalker™, an improved and updated version of the IntroTalker™ offers digitized speech (expandable to a maximum of 30 minutes), MINSPEAK, improved memory technology that will allow retention of stored messages even when the device is without power, the software previously available only on more advanced devices (e.g., icon

prediction) and an improved, streamlined appearance.

When asked about the kinds of consumer input and involvement in the development and revision of such a product, Barry Romich reinforced the idea that the *clinician-consumer* provides regular feedback that helps PRC refine their devices. Specifically regarding *user* input, he noted that PRC developers have access to AAC users when they visit the site for assessment and training sessions, or when clients and families come to the MINSPEAK™ Learning & Resource Centre (a non-profit clinic for MINSPEAK™ users.) He also noted that the Beta Testing and MINSPEAK™ Application Programs at PRC directly involve AAC users.

Julie Patterson, coordinator of the Beta Testing program at PRC, describes the process as collecting the needs identified primarily by professionals, developing a prototype at PRC and then providing that device to AAC users for a trial period (typically three months.) Revisions to the design are then made based on feedback from the users. While there certainly is a structure in place to formally include device users in the development process at PRC, both Barry Romich and Julie Patterson agree that the majority of feedback PRC receives from the field is from professionals.

If the discussions I've had with device developers for this article reflect the state of affairs for others in general, then at least in one sense my intuition about the process of user feedback is correct: While some channels appear to exist for (some) disabled individuals to be involved in the testing and refining of new products, by and large the users of AAC devices don't provide a lot of ongoing feedback about device performance and improvement. Clients will likely continue to rely on clinicians to perform this duty until clear and direct channels of communication are established that are largely independent of clinicians and other profession-

als. Certainly clinicians need to maintain a good working knowledge of available technology to best serve those clients and families entering the system, and I sincerely hope that established clients will continue to look to clinicians like myself as sources of information and advice about their communication needs. However, I feel strongly that if direct communication between AAC users and developers was more routine, developers would have better information, better products would result, and the users of those products would feel increasing ownership and control of the process. An excellent way for the process to begin is for AAC users to start to forge their own links with developers with letters, FAXes, phone calls, and visits. Speaking as a clinician, I would encourage all professionals to do what they must to help their clients achieve these ends. This certainly does not diminish the clinical role, but rather allows it to be seen as one of actual empowerment. I like to think that this moves us one step further away from the "complete consumption" model, back towards the reasons why many of us chose this job to begin with.

I will be sharing further perspectives on this topic in future issues. Due to space limitations they could not be included this time. I invite readers who know of situations that either reinforce or refute the observations I have cited, to write to me c/o **Communicating Together.** §

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Outstanding Consumer Lecture

ISAAC Secretariate (see page 10 for address)

ADVOCACY AND EMPOWERMENT: RIGHTS FOR EVERYBODY

NOLA MILLIN



It seems advocacy and empowerment have really become popular words in the nineties. Advocacy is simply the state of standing up for your rights or standing up for the rights of someone else. Empowerment is the state of being given the necessary facts to make a decision. In some ways advocacy and empowerment are similar. A person has to have facts, so she or he can advocate for a specific purpose. Advocacy and empowerment have been around for a long time. Most likely everyone has done or has gotten some sort of advocacy and empowerment in his or her lifetime. When we think about it, advocacy and empowerment are very common. Lawyers and doctors are advocates but they usually allow their clients to make decisions; parents are usually advocates for younger children but they give older children the skills to make decisions; friends are usually advocates for other friends and help them get needed information. For most people, advocacy and empowerment occur at many times during their lives.

Unfortunately for the AAC user, advocacy and empowerment can be difficult. Obviously, communication

is a vital part in both of these procedures. To become empowered, a person has to make it known that he or she wants to know the facts of the issue. For some consumers, obtaining facts and information isn't a natural part of their lives. They have had people such as professionals, caregivers, and parents making decisions on their behalf for so long that they simply don't know how to get the needed information. Another disadvantage is that for some AAC users the challenge of making themselves understood takes so much energy that the additional task of obtaining information can be overwhelming. Even for people who have "normal" speech, getting information can be difficult. I've seen people spend an entire day getting the run-around on the phone just to get answers to questions. Empowerment isn't easy, especially for the AAC user, but with a lot of perseverance it is possible.

Empowerment and advocacy can't be easily taught; they are aspects that are learned along the road of life. However, people who are involved with the AAC user can help the person get the skills needed for empowerment. For some reason I was born with a persistent nature better known as stubbornness. My nature helped me to become inquisitive at an early age. Fortunately, my parents supported my inquisitiveness which helped me learn how to make decisions. Obviously, they didn't allow me to make a decision that would put my life at risk but they did allow me to make some foolish choices. These ridiculous choices taught me how to analyze information and facts before coming to a decision. I, also, learned that I have to accept the consequences of my decisions. I imagine it was tough for my parents, or for any parents, to see

their child make a foolish decision, but at the same time, it gave me valuable lessons to live by. Today, I live independently and I know how to get the necessary facts that empower me so I can make many of the decisions I need to make.

Decision-making is a big part of empowerment. When someone is empowered, she or he is in control of the situation. I have spoken many times of how important it is for consumers to be involved in decisions that will affect their lives. Because I'm a "take charge of my life" type of person, empowerment comes easily for me. My doctors and other "professionals" have had no choice but to deal with me directly and answer my many questions. There are a few tricks I've learned about dealing with professionals. I type notes to them stating my problem and I go into their offices alone. If I need to ask further questions, then I use my AAC device. I have "trained" the professionals (ie. doctors) to be accustomed to me and realize they don't have a choice but to deal with me. They know that they have to give me the information about my condition because I'm the one who makes the final decision.

Being empowered doesn't mean having to get the needed information for a decision by yourself. A person can turn to other people for help. This is where one aspect of advocacy comes into place. When a person is an advocate for another individual, he or she is acting on behalf of that individual. In most cases, an advocate is someone who will listen to the individual and actually do what they say; advocates don't make decisions, they just gather the information so the individual can make decisions. For me, having an advocate was necessary. After my parents' deaths, I had other people who advocated on

my behalf and helped me to achieve my goals. Teachers and therapists fought on my behalf which meant I could live independently at age 17. My teacher was able to get me into a regular high-school system because he didn't give up after the first "no". Once these people had advocated and gotten the needed information, they allowed me to make the final decision. This instilled the value of being empowered in order to come to a decision.

I realize that I have many friends who, from time to time, have to become my advocates. Since I'm an AAC user, I have difficulty making phone calls so I get friends to make them for me. I also realize that some people aren't as blessed as I am. This is where the new Advocacy Legislation in Ontario, Canada, will enter into play and be a big help to individuals. I'm not going to spend a lot of time discussing this legislation, since it would take up too much room in this issue. Basically it states that all disabled people are entitled to have advocates. Again, advocates won't make the decisions but they will be able to get information so that people can make the decision. Advocates empower people who might not otherwise be empowered due to their circumstances.

I took part in a conference for adult Bliss users in Ontario on October 22. During the group discussions, the subject of empowerment and advocacy were addressed at length. I was pleased to see that everyone agreed that AAC users have to advocate in order to be treated equally in society. AAC users can be ignored unless we make our needs known. Often someone who uses a device doesn't participate in group discussions whether it's in a classroom environment or in a meeting. It was interesting to see how everyone who was at the conference felt comfortable enough to use their AAC device. We identified the need for the general population,

and professionals, to become aware of different kinds of AAC devices. There are a lot of misconceptions about AAC devices that need to be cleared up. One person stated that a school district had refused to start using Bliss symbols with a child because they thought Bliss was too difficult to understand. This is not an issue of whether Bliss might be more or less beneficial than another symbol system the child is now using. The point was that the child wasn't given an opportunity to try Bliss due to somebody's ignorance of it. In this case, an advocate for Bliss might have been useful.

Another aspect that came out of the Bliss Conference was the fact that AAC users have the ability to advocate for each other. I know there have been many times when I have had to speak up for my friend who is totally dependent on her AAC device. My speech is understandable to those who are close to me so I'm able to speak on behalf of my friend. Sometimes, all I have to do is to tell the staff that she needs her device. At other times, I've had to try to guess at what she wants when her device isn't working. Despite the circumstances, AAC users can help each other in many ways. Sharing information, helping someone communicate, or instructing an attendant on how to assist the person are all ways in which we are able to advocate for one another. I know I always feel good when I help my friend communicate. It was great to see consumers helping each other at the conference. We know how it feels to be dependent on an AAC device so we make the best advocates for each other.

Regardless of the cause, empowerment and advocacy can work together and be a part of most everyone's life. I feel that if people have the ability to make decisions then they have the right to do so. Empowerment in itself, is a choice.

A person can choose to be empowered or can just sit back and accept whatever comes their way. When a person is empowered and knows information about certain issues then she or he has the ability to share this knowledge and even advocate for another person or for change. Empowerment and advocacy often work simultaneously. Because individuals are empowered they can advocate for something or they can be someone's advocate. When individuals seek the advice of an advocate (in whatever form) then they will become empowered in the particular area. Once they know the facts of a certain issue then they can be involved in whatever decision needs to be made.

In my mind, empowerment and advocacy are essential for AAC users because we have been silent for too long. Despite the difficulties, it's time we help each other by advocating for our rights. People need to know that AAC users can speak up (literally) and have the right to be heard about issues that are important to us. Regardless of the means of communication we use, advocacy and empowerment for people with disabilities is here to stay. It's our choice whether or not to be empowered and advocate for further change. The more we speak up and advocate for the rights we must have, the more empowered we will be to use them. The time to speak up is now! §

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The Ultimate Paradox: Health Care as a Commodity

GEB VERBURG

Lately I have bumped into an interesting and potentially very disturbing contradiction. On the one hand we tell people with disabilities that they are empowered and must make their own decisions. On the other hand we (i.e. professionals) and health care providers continue to believe that it is our job to: "provide care", "select symbols", "prescribe AAC devices", or "be a facilitator in the Alternative and Augmentative Communication process." That is, on the one hand we are trying to surrender responsibility and on the other we are (I won't say *desperately*, but it is *definitely*) persistently holding on to our traditional role as minor gods and goddesses in the health care field, telling people what to do, how to do it, and what to do it with. That does not add up. We, health care professionals and researchers, have to make up our minds and decide whether we are for empowerment and independence or whether we want to continue to adhere to the medical model.

Consumers are Responsible for their Life Decisions

First, let me draw what I think is a logical consequence of the decision to give responsibility to the person with disabilities. You all know that the basis for such a decision is that a person with a disability is not sick, not incompetent and can and should make decisions about their own life, health and care. They may seek out help or support or advice, but the person with the disability is in charge, is responsible, and is capable to make those life, health, living,

working, transportation, mobility, communication decisions.

Already I can hear the: "Yes, but..."s, "Oh, no!"s or the "No way!"s. Oops, what went wrong? Even the most forward thinking professionals may say: "Yes, consumers with disabilities can be responsible, but 'not for their communication devices' or 'not for their vocabularies' or 'not for their mobility devices.'" And that of course is the paradox. We do want consumers with disabilities to be empowered and independent and autonomous — as long as they continue to let us decide the important things like what kind of wheelchair they need, or what kind of AAC device they can really use. That of course doesn't fly! That is the worst possible instance of professionals wanting their cake and eating it at the same time.

Health Care Services as a Commodity

Independence means independence. It means having the right to choose the right AAC device but of necessity also the right to choose the wrong AAC device. It must include the right to learn from one's mistakes in the most damaging way possible which certainly describes a client with a poorly chosen AAC device. Until professionals allow persons to make their own choices, even beyond health care related things such as AAC devices, and wheelchairs, we are not empowering our clients. I believe that this attitude on the part of some professionals is dishonest both to themselves and to their clients. They are running the risk of keeping their clients dumb and dependent, all for the ostensibly noble reason "we are protecting the client" (from himself or herself). Some professionals will believe, for

a little while, that they need to protect their clients. I hope that they too will soon find out that their protection is not helping the clients but is just preserving the traditional role of the professional.

Sought: New Professionalism

We are not protectors or wards of persons with disabilities anymore. We also do not—and if we still do—should not have a monopoly on control over the health or other life decisions of persons with disabilities. For able-bodied adults, nobody but the person has the right, within ample limits, to decide what to wear, what to ingest, what to drive, what to sit on, what tools or appliances to use or not to use.

Persons with disabilities are dependent on a physician, therapist, or other specialist to choose the chair they sit on, the brace they wear, the switches or joystick they must use, the glasses, the orthoses or prostheses they must wear. To be dependent for such services upon a physician or specialist is repressive, especially if she or he is the only one in town and has the peculiar and unscientific attitude of "not believing in Device X." Such things happen and are in my opinion classifiable as forms of soft abuse. They should not happen anymore.

Until every person has the right and opportunity to choose to accept or reject prescriptions and has an equal right to go to another specialist for a second opinion if he or she so chooses, until that time we are still discriminating against people with disabilities. Only when the service of professionals becomes a commodity, something that persons with disabilities can come and buy without having to surrender all or part of their independence at the gate, only then can we speak of autonomy and independence.

How Does the Researcher Play This Game?

In research the paternalism and the persistent remnants of the medical model come to the fore in, among other things, the evaluation paradigms. Evaluation studies tend to investigate whether a device or treatment works, or evaluators look for reasons why devices were not accepted or for ways in which research can help to make prescriptions more effective. Researchers are in effect carrying out studies to decide for the clients what works and what does not work for them. Evaluations also are used to find out why clients do not like (accept) devices. Finally research investigates how other people can better decide for the client.

Let me take these peculiar practices into real world consumer practice. The examples may be a little trite but ... studying the effect of a treatment is somewhat like hiring someone to tell you whether the hairdresser gave you an appropriate (or effective) permanent or haircut. Evaluating a device is like paying a consultant to tell you whether you bought the right car (after you signed the purchase agreement). In both these cases consumers or clients are the best judges of the results of the actions. And if they make a mistake then they will suffer for a while. As a result the customer may decide never to go back there again.

If we really believe that the client is independent, responsible, and

autonomous than the studies we require are not so much studies that decide for the client, but rather studies that help us better serve the new customers, e.g. needs identification studies and market analyses. Customers (who happen also to be the subjects in the experiments) will, by their choice patterns decide what works and what does not, and whether or not they like device A or B or C. That is empowerment in the commercial market.

I think we should give it a shot. I don't think that this model of service purchase means that all professionals will be out of work. It will require a different attitude, first in the field of rehabilitation and I hope some day soon in that of medicine in general.

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PAUL'S PLACE

Empowerment, For You and Me

PAUL MARSHALL

A man sat watching the sea one evening after a hard day. As he watched the waves going in and out, he saw that each one was forever changing until it broke and returned into the sea to create a new and different wave to repeat the process. He thought about how life is also forever changing, never staying the same. He reflected on how the waves are like seasons in one's life. He realized if he viewed his life as an ongoing process of constant change and learned from this, he would have empowerment in his life. As the sun went down he began to see the light differently, but the waves were still moving. He began to see the beauty in the reflections.

Each of us live where the waves of life don't overtake us. The waves

can take us under if we don't have a positive outlook. We can learn to reach inside and find empowerment. It takes a view that is higher than education, job, relationship or any circumstance that we may encounter. Real empowerment flows from within.

There are two theories: a) empowerment is learned and b) empowerment has to flow from inside. Both are right, but the skill of empowering one's self is a lifelong process. It is learned and then developed and nurtured. It is food for the soul that will be the driving force to overcome trials. It is the self-knowledge and self-fulfilling passageway to allow a human spirit to take flight.

No thing or no one can empower another. I might be able to show you ways to empower yourself, but only you can do it. Trials of being "nonspeaking" or having any handicap can be overwhelming. The

questions outweigh the answers. How can we empower ourselves? Many "normal" people do not have empowerment. Almost everyone has something that keeps them in bondage, prevented from soaring high and having peace, joy and freedom. Real empowerment comes from our reactions. If our actions are negative then we reap that view. Empowerment is not viewing only the good, it is learning to accept what cannot be changed, but always trying to make a difference.

The bondage of our past, our self-pity, our anger toward society, and our self-centredness can keep us from having strength. Our lives are like the waves, as they ebb and flow. The waves that we make in our lives affect the world around us. Our lives are but pebbles on the beach in history, but in us there is a form of empowerment that can touch mankind.

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Assessing "Carla"

ALAN HUDSON

Alan Hudson Ph.D. is an Australian psychologist who was one of a two-man commission set up by a custody court to assess "Carla's" Facilitated Communication. He submitted this article in response to the letter from Rosemary Crossley, published as a Perspective in the March, 1993 issue of Communicating Together.

In the letter published in the March 1993 issue of **Communicating Together**, Rosemary Crossley makes several comments about the case of "Carla". As I was one of the psychologists involved in the case, it is incumbent upon me to address some of Crossley's comments. First, however, I would like to provide some background information about Carla.

Carla was a twenty-nine year-old woman who was considered to have a severe intellectual disability. She lived with her family and attended a local day centre for people with an intellectual disability. While attending the centre during 1990, she made allegations, via facilitated communication, that her father and brother were repeatedly raping her. The accusations were made on several occasions with several facilitators. The police were involved at the time but decided not to press charges because of concern about evidence provided via facilitated communication. However, as a result of the allegations, Carla was removed from her home by the relevant government authority in late 1990.

Not unexpectedly, the family denied the allegations, and during 1991 made an application to the

Guardianship and Administration Board (GAB) to be appointed the legal guardian of Carla. Success with their application would enable Carla to continue living at home and give some say to the family regarding Carla's use of facilitated communication. The GAB hearing was held ultimately in February 1992, but prior to this myself and another psychologist were invited to conduct an assessment into Carla's ability to validly communicate using facilitated communication. Our conclusion was that Carla did have a severe intellectual disability and could not communicate using facilitated communication. Complete details of the outcome of that assessment have been published (Hudson, Melita, & Arnold, 1993). The following comments are to do with Crossley's criticisms of that assessment.

To begin with, Crossley claims that "The communication tests were done with a new and untrained facilitator" (p. 14). Carla was facilitated by several staff at the day centre she attended. As part of the extensive discussions which took place with centre staff prior to the assessments, it was agreed that the centre would select the person to facilitate Carla during the tests. It is unthinkable that the centre would send a new and untrained facilitator, particularly given the seriousness of the allegations of rape that were germane to the case.

A second point that Crossley makes is that Carla was "a person with major motor planning problems." This assertion appears to be made on the basis of the administration of a brief apraxia screening test administered by Crossley during the Guardianship Board hearing. A summary of the results of this testing was sent to this author by Crossley after the hearing was over. Carla had

never been diagnosed by an appropriately trained person as having any form of apraxia. On the contrary, an experienced neuropsychologist, on hearing a detailed description of Carla's fine motor skills during a consultation with the author, indicated that it was extremely unlikely that Carla had any motor planning problems.

A third point made by Crossley which merits comment is that Carla had "word finding problems" (p.15). The selection of articles in the first 1992 issue of *Topics in Language Disorders* summarize the complexities surrounding the nature and assessment of this disability. However, to assert that Carla failed the assessment because of word finding problems is not logical. If this putative disability prevented Carla from successfully answering questions in conditions C and D of the assessment (the conditions in which the facilitator was screened from the questions), then it should also have had the same effect in conditions A and B. She "correctly answered" eight out of ten in A and four out of ten in B. In both C and D she answered zero questions correctly. If Carla did have a word finding problem, it would have manifested itself across all four conditions.

Crossley has previously argued that the potential existence of word finding problems makes the experimental assessment protocol used with Carla inappropriate. An interesting pair of studies have addressed this issue further. Moore, Donovan, Hudson, Dykstra, and Lawrence (in press) used the standard protocol to assess the ability of eight disabled people to validly communicate using facilitated communication. The conclusion drawn by the researchers was that not one person could. The facilitators considered that the poten-

tial presence of word finding problems made the methodology inappropriate. As a consequence, they were invited to develop an alternative methodology. They then developed a methodology which dispensed with the single word or short answer questions, and replaced them with a procedure involving extensive discourse between disabled person and facilitator. The alternative methodology employed was as follows. The person with the disability was shown an object (e.g., a torch or a book) when the facilitator was out of the room. The facilitator then returned and engaged the person in general conversation. They could communicate for as long as they liked about whatever they liked, but had to then state what the object was. Five subjects were involved in a total of 21 trials, but not once was the facilitator able to identify the object (Moore, Donovan, & Hudson, in press).

Another point Crossley makes is that "The Board refused to see Carla communicate in person" (p. 14). It is true that the Board did not allow the use of facilitated communication in the hearing room during the hearing. Board members were, however, able to see Carla using facilitated communication. Every minute of the testing was videotaped and the tapes were given to the Board. The quality of the tapes was very good from both visual and auditory perspectives. It is also salient to note that every minute of the testing was observed (through a one-way screen) by three observers. One of the observers was a lawyer representing Carla, one was a psychologist representing Carla's family, and the third was an independent person from the Office of the Public Advocate. Any of the observers could have stopped the testing at any time if it was thought that Carla was uncomfortable or anything untoward was happening during the testing. The testing was

never stopped and Carla appeared to be enjoying the activities.

A final point regarding Crossley's comments relates to her statement that the Guardianship Board found that Carla "could not communicate through spelling" (p. 14). A more accurate statement would be that the Board found that Carla could not communicate using facilitated communication, and that the facilitators were influencing the communications. The inference is, of course, that the facilitators were the source of the communications.

The quantitative assessment of Carla's ability to communicate using facilitated communication is one of the first such assessments reported in the scientific literature. With the explosion in the use of the procedure many other studies are underway or completed. The Autism Research Institute (1993) reproduced a summary table of such research constructed by Gina Green of the New England Center for Autism. The data are compelling. In only three of 187 assessments is the validity of facilitated communication supported. The one study involving the three successes has been criticized on methodological grounds.

Given this general lack of empirical support for the validity of facilitated communication, serious questions must be asked about the precise nature of it. This would appear to be particularly urgent given the court cases and litigation associated with the use of facilitated communication (Autism Research Institute, 1993).

As has been argued elsewhere (Moore *et al.*, in press; Hudson, 1992), there is a need for a thorough evaluation of the theory underpinning the technique. One difficulty in this regard is that a clear and comprehensive statement of what the theory and practice of facilitated communication is has never been published. The available literature tends to focus on "how to do it"

rather than "why." The current author has indicated to Rosemary Crossley that such a theoretical rationale is overdue given the extensive usage of facilitated communication. If there is no sound theoretical base for the technique, and there are no convincing data to show that it works, then why is it being used at all?

An interesting aspect of the Carla case was an incident which occurred on the last day of the ten-day Guardianship and Administration Board hearing. The incident was reported in *The Sunday Age*, a Melbourne newspaper, on 23 February '92 (Heinrichs, 1992). On the final day of the hearing, after all of the evidence had been presented and the Board was receiving final submissions, Carla's solicitor said that she had very clear instructions from Carla that she wanted to speak to the Board. A staff member of the DEAL Communication Centre facilitated Carla in her statement. The statement needs to be viewed in light of the following facts. The allegations of rape made by Carla, through facilitation, were made throughout 1990, culminating in her removal from her home in late 1990. The allegations stood throughout 1991 when the application to the Guardianship Board was made and the validity testing was conducted. They also stood until the beginning of the Board hearing in February 1992 and then throughout the first nine days during which evidence was heard. The essence of the statement made by Carla on the tenth day was that she had lied about the allegations in 1990 and that she now apologized!

On the basis of the extensive evidence it heard during the ten-day hearing, the Board determined that Carla could not communicate using facilitated communication and awarded guardianship jointly to her mother and her sister.

See Editors' Note on p. 23. §

Facilitated Communication Techniques: Can AAC Professionals Delay a Pro-FCT or Con-FCT Stance?

BEVERLY VICKER

Beverly Vicker is a speech language consultant at the Institute for the Study of Developmental Disabilities at Indiana University, Bloomington, Indiana, USA. She has worked in the AAC field since the late sixties and always brings a thoughtful perspective.

Understanding My Perspective

I am writing this response to Howard Shane's recent article in **Communicating Together** (June, 1993) because I wish to suggest to other AAC professionals that despite the very nonsupportive studies that have been published about facilitated communication techniques (FCT), it may be premature to say that no one can legitimately communicate while being facilitated. I write this response as someone familiar with traditional AAC (Zangari, Lloyd, and Vicker, in press), the literature and training on facilitation and with autism. With reference to the latter, I have a background that includes direct service with this population and extensive experience in providing technical assistance and training to families and service providers regarding programming issues and challenging behaviours. Since my current role does not include direct service responsibilities, I do not have an emotional investment in FCT because of client/service provider relationships. My motive, instead, is to share some information about autism and to suggest that as AAC professionals we need to ask additional questions and to explore certain areas before we make pro/con decisions about FCT.

The Peculiarities of Autism

As a disability, autism is different from cerebral palsy, traumatic brain injury and a host of other medically based disorders. While other disability groups may share some specific traits with autism, it is the specific cluster of characteristics and the social impairment which makes autism unique. It becomes difficult to talk about individuals with autism as a homogeneous group, however. Individuals vary along a continuum for cognitive abilities, communication skills, academic competencies, social interest/abilities, flexibility, motor skills, functional problem solving abilities and initiation of spontaneous behaviour. The person with autism could also have one or more of the following: mental retardation, a vision or hearing impairment, a compulsive-obsessive disorder, depression, epilepsy and a personal history that includes abuse or institutionalization. The disability becomes increasingly more complicated as new information is derived from medical research and from the writings of articulate high functioning adults with autism (Grandin, 1984, 1990, Baron and Baron, 1992, Williams, 1992). I agree with other AAC professionals that if given adequate programming, many with autism (even possibly most) could use conventional AAC intervention. I am not too certain, however, about the *nonexistence* of a subgroup with a movement disturbance that may initially need the techniques of facilitation for accessing an AAC display/device. If the disturbance exists, so do the possibilities for a continuum whereby some individuals may need minimal facilitation to move to independent communication and others may need prolonged supported assistance.

My hesitancy in dismissing the possibility of a movement disturbance

is based on several observations. First, for at least ten years some people in the autism field have speculated about the possibility of an "apraxic-like" component underlying the extreme silence of some individuals with autism. Extensive research on this supposition did not occur. The degree of subject cooperation that would have been needed to use experimental procedures or traditional testing and the difficulty of subject matching did not encourage active research on this topic. Instead the speculation was based on numerous histories and observations of individuals who may represent the extreme of yet another continuum associated with autism. Parents have reported limited vocalization during the infancy of their children; professionals have observed a remarkable lack of sound even for self-stimulation purposes. The exceptions to silence were automatic responses like crying or laughter and some sounds/words which may have been produced when the person was highly stressed.

Similarly, it is difficult to dismiss the reports and observations of the extremely low rate of initiation of some other behaviour by some people with autism. Environmental conditioning or the degree of cognitive impairment may not be a sufficient explanation. Unlike many older adults who spent a lifetime in institutions, today, most children with autism remain with their families until the late teens or adulthood. The histories of limited imitation for some of these children are incredible.

The issues of literacy and facilitator influence are also prime considerations. Although it is true that many individuals with cerebral palsy, for example, may have difficulty learning to "read", this is not true for individuals with autism. The latter group is usually very focused

by visual information. Most individuals with autism can “read” to some degree or can easily learn to “read” some words within contextual settings. The problem for some of these individuals, however, is that the words may not be associated with semantic meanings. This can be described as “word-calling” rather than “reading”, in the traditional sense. Individuals with autism often have considerable capacity for rote memory information such as printed words; certain types of print such as the credits at the end of movies or TV programs can become particular literacy fixations. The ability to read some words, however, does not automatically mean that the person with autism can spell the words or use them meaningfully as expressive output. Just as many typical pre-school children teach themselves to read before they enter a formal educational program, it is not inconceivable that some individuals with autism can teach themselves to read and comprehend text. Some children who are very superior at reading text but who exhibit difficulty with comprehension are described in the literature as “hyperlexic” (Kiestner, Robbins, and Haskett, 1988).

Other children, however, seem to have a very difficult time learning to read and appear to have a learning disability in addition to autism. These latter children may not have the tremendous memory abilities of the more typical children with autism; they may constitute a different subgroup which may or may not overlap with candidates for a possible movement disturbance category. Thus, there may be several subgroups within the autistic continuum who differ in literacy abilities /skills and in their potential to use spelled communicative output.

Another area to be considered is the frequent use of peripheral vision by some individuals with autism. These individuals may have to be

helped to look more directly at the communication display. Whether this type of vision and an outstanding visual memory would enable someone to use a keyboard with a high degree of accuracy. I don’t know. I suppose it is possible for some individuals if the rate is slow enough or if someone has an extraordinary visual imagery capability. I really question it when the targeting rate is fast. It might be one thing to remember which drawer or which book contained something, but to know without looking which key corresponds to a letter based on a visual image would seem to be difficult. Again research is needed to explore this possibility.

With regard to facilitator influence, I don’t doubt that there are some well-intentioned people who are directing the message output of the facilitated. I am not convinced, however, that no one is producing his/her own thoughts. I come to the former conclusion based on what I have observed and from extensive contact with motivated caregivers. Rosemary Crossley has said that the best FC user is able to produce only 200 words of spelled output per hour and thus there is a need for looking at acceleration techniques. If the facilitator indeed waits to feel the pull of the facilitatee’s forward movement toward a display, this might be a reasonable estimate, particularly if the amount of resistance needs constant monitoring. Instead, many facilitators may not be waiting for that pull and may not be attempting to be in synchrony with changing resistance demands; they may instead be making interpretations of message intent based on one or two letters, on context, on assumptions or on best guess.

AAC professionals know that they may make similar interpretations with some AAC users who do not have autism. Even though they might have some difficulty with

conversational repair, hopefully most non autistic AAC users would let the communication partner know if their message was incorrectly presented. Although I don’t have data to support my supposition at this time, I would bet that few individuals with autism would consistently protest if someone did direct their hand or incorrectly ascribe meaning to their message.

The exception might be if the person really wanted to request something and that was ignored. To a person with autism, something as non-meaningful or non-egocentric as naming pictures may not seem that important to that individual; he or she may also not realize his or her inherent responsibility for insuring the accuracy of communicative responses. In some areas many people with autism view the world from a very different perspective than a conventional one and this must be remembered as some of the negative FC study results are reviewed.

In conclusion, in a few years, we may be in a position of knowledge to make definitive or qualified statements about facilitated communication techniques. For now the AAC professional will want to exercise caution as he or she experiments with the technique because the negative consequences of facilitator influence can be dreadful for individuals and their families. It is too soon, however, to close our minds to the possibility that facilitation might help some individuals to communicate and to enjoy a greater participation in our society. Instead of putting energy into polarization activities, AAC professionals need to share insights and to generate new questions that can guide further research efforts.

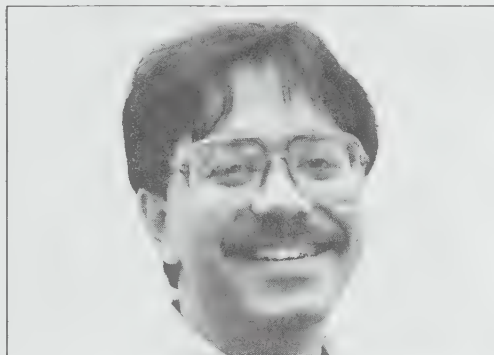
Readers interested in obtaining questionnaires relating to FCT, developed in Indiana, can contact Beverly Vicker, FAX : 812-855-9630.

See Editors’ Note on p. 23.

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FC: In Search of the Perfect Artichoke

STEPHEN N. CALCULATOR



Stephen Calculator, Ph.D., CCC-SLP is a professor of Communication Disorders at the University of New Hampshire, Durham, NH. He is presently the chair of the Facilitated Communication ad hoc committee for the American Speech-Language-Hearing Association.

In the two years which have passed since my introduction to facilitated communication, my feelings about the value of this method of communication have fluctuated, often within a single thought. Like many, I was indoctrinated via a workshop at the FC Institute at Syracuse University. At that time I found myself mystified as an audience enthusiastically nodded in response to presenters' suggestions that much of our understanding and preconceptions about mental retardation and individuals with severe disabilities were potentially inaccurate. We were told about individuals who were capable of extracting information about their world and mastering modes to convey such knowledge (e.g. literacy skills) in the absence of formal instruction and, in many cases, despite years of institutionalization. More compelling, these insights were shared by FC users themselves.

Conjectures about movement disorders, word finding problems, and the like were offered (or interpreted by others) as facts explaining why facilitated communication was effective.

Questions about empirical support for claims presented, rationale for procedures, etc. were dismissed as the banterings of skeptics. Were we truly to believe that this method, in which cognitive and linguistic competency (and spelling ability) was presumed, could apply to a tremendously heterogeneous population in which no bounds were defined. Were we to accept the notion that as different as these individuals were from one another, one thing they all shared was an aversion to testing/having their abilities questioned in the form of validation and related testing?

But what about the poetic and even prophetic messages these individuals were allegedly conveying? Were they truly the FC users', or could they instead be the unwitting messages of facilitators who employed FC users as human props in the first reported monologues involving two persons? Before the obvious was questioned, the method proliferated and the risk of inquiry (in a time of political correctness) led many of us to look the other way. Recently, however, investigations of the efficacy of this method have been encouraged. Unfortunately, much of this work has not been precipitated by investigators searching for more effective instructional methods for individuals with severe disabilities. Instead, it has been rationalized as a reasonable response to a worser evil — mistaken allegations of sexual abuse and similarly shocking anecdotes popularized in the media.

Personally, I am now at a point that I can say with total confidence that I haven't a clue what is going on in this area. Research points us in many directions, often divergent. Experimentally controlled designs have yielded a vast amount of information which irrefutably demonstrates that facilitators can *and do* influence messages attributed to FC users. These investigations have also

demonstrated that facilitators are unable to detect when they are influencing messages, much less determine the extent of this influence. Conversely, qualitative research has recounted numerous examples of individuals relating novel information, and/or communicating in ways which lead facilitators and others to conclude that some messages are indeed those of the FC user.

My own research (in preparation) muddies the line between these two methodologies. Seventeen consecutive subjects have demonstrated that in the presence of experimental controls (e.g., white noise, barriers, etc.) which deprive their facilitators of information necessary to respond to examiners' questions, subjects fail to exhibit unexpected literacy or communication skills. However, errors are rare on *these same tasks* when the facilitator has access to the information which is presented to the subjects. Before dismissing these latter findings as further evidence of facilitator authorship, we need to look *qualitatively* at some of these responses. Why would a facilitator author a response to an examiner's asking a subject if they wanted to take a break by typing, "LEAVE A MOMENT TO URINATE"? Why would another individual, asked to explain why he was unable to respond to a particular experimental task even though his facilitator indicated he was doing school work which was significantly more demanding, typed, "IM EXUDINC NERVES" (I am exuding nerves)? Certainly, these are not typical responses of typical speakers — but are they different enough to suggest authorship by FC users? On another occasion, a subject was asked how the words, 'Monday, Tuesday, and Wednesday' were alike. What was similar about them? His response, "GO TO AL SKOOL" was different from that given by any one of over five hundred participants at conferences in which I have recently presented. Typical

responses authored by these participants have consisted of "Week days" and "Days of the week." Again, the fact that the facilitator heard the question asked of the subject leaves the issue of authorship open to debate. However, I would argue that collectively, these unexpected messages are too intriguing to dismiss without further consideration.

The story line is further complicated in instances of a double sided picture task in which the facilitator was shown a picture of statues while the subject viewed a picture of fruit. Facilitator authorship would be suggested if the subject typed the word "statue" (a picture which he was not observing at the time). How do we account for the subject instead typing, "DIFFRNT A BUST" (Different types of busts)? What type of dynamic could explain such outcomes — could the facilitators not only be authoring messages for subjects but be doing so with words and phrases which might be more attributable to these subjects (misspellings, idiosyncratic phrases, and so forth)? What processes would explain this type of code switching?

At this stage of my lack of understanding regarding this phenomenon, I am intrigued by many issues. Despite the controversy surrounding this technique, it continues to gain momentum as a method of choice (if not of last resort) for many adults and children, representing a variety of etiologies (autism, Down Syndrome, Rhett Syndrome, Angelman Syndrome, and so forth). Is this an indirect statement of our frustration with outcomes following the provision of AAC systems? With \$10 (to construct a letter board) and a couple of hours of training, we could promote (or imagine) communicative gains which hundreds of hours of AAC instruction did not begin to approximate. The FC controversy should encourage greater introspection regarding the efficacy of AAC intervention as well.

Educational and related programs are now being designed and monitored on the basis of FC output. The validity of this output, and the possibility that it bears no relationship to the actual abilities or desires of the FC users are not considered. One student I have known for several years is now on the honour role at his local high school. (Note: he completes all of his tests and assignments using facilitated communication, although extensive controlled testing indicated a lack of the most basic literacy skills and no evidence of an ability to author any messages unbeknownst to his facilitator.) This brings us to another frightening prospect.

Facilitated communication has been tied to inclusive education for many students and schools. By operating under an assumption that some of these students are academically competitive, the challenge of offering appropriate educational programs in regular classrooms was mitigated. For many families, data contradicting the efficacy of FC now threatens their children's rights to be educated in inclusive classrooms. It is critical that these two issues (FC and inclusion) be viewed in proper perspective. Effective communication of any type promotes successful inclusion; inclusion, however, should not be contingent upon a predetermined level of communicative effectiveness.

We find thousands of dollars being invested in FC curricula, workshops, and related training. This is somewhat remarkable in that the technique has yet to be defined (in a standardized manner), the characteristics of effective facilitators remain undetermined, and the efficacy of the method itself is unknown. Are FC experts, themselves, good facilitators? Is an individual who is consistently successful introducing this technique a poor facilitator (unaware of their influence in authoring messages) or a good facilitator (able to draw messages from individuals with whom others have been unsuccessful)?

Two years ago, I was confident that facilitated communication would be a passing phenomenon of great social significance, yet little communicative value. It raised fascinating issues regarding human behaviour. For example, are we capable of treating people in a respectful and dignified manner, exhibiting a genuine care and interest in them, and voluntarily spending time with them (as opposed to scheduling interactions as per a predetermined instructional program and/or job expectation) without assuming they are intellectually capable? Various collateral effects have been associated with facilitated communication. For example, subjects have been reported to exhibit more socially appropriate behaviour, display better attending skills, exhibit more on-task behaviour, etc. Teachers, parents and others have reported higher expectations and more positive perceptions of persons following the "successful" introduction of FC.

What risks (e.g. reversing these positive outcomes) are inherent in discounting communication skills on the basis of outcomes of validation testing? Do we encourage and perpetuate perceptions (of competence) when empirical data suggest otherwise, given we are unwilling to accept the risk that disclosing "true" experimental outcomes may precipitate a withdrawal of positive outcomes in the quality of individuals' lives which followed their introduction to FC? These are haunting issues which tax the limits of what constitute appropriate and ethical practices. They are particularly troubling when initiated by parents who are unwilling to debate the qualities of good science at the expense of their children's immediate welfare.

Two years ago, I was dismayed after spending two days of my life learning a technique which I thought was simple enough to have been taught in a matter of minutes. Today, I am not confident that the breadth of this phenomenon, in all its complexity, will ever be understood.

See Editors' Note on p. 23.

Responding

ROSEMARY CROSSLEY

*In the June issue of **Communicating Together**, we published the Perspective of Howard Shane, entitled, "FC: Facilitated or 'Factitious' Communication" and in this issue, one of our Perspectives is a response by Alan Hudson to a letter by Rosemary Crossley, printed in the March, 1993 issue. Here, Rosemary Crossley of the DEAL Communication Centre, Victoria, Australia, the originator of Facilitated Communication Training, is responding to both Howard Shane and Alan Hudson. We regret that space constraints prevent us from printing her entire submission; however, her full paper is now available through the Sharing to Learn Informal Publication Series (See Editors' Note on p. 23).*

In the June issue of **Communicating Together**, Howard Shane wrote, "Facilitated Communication is not a legitimate form of expressive communication" (Shane, 1993). In this issue, Alan Hudson writes, "...serious questions must be asked about the precise nature of facilitated communication". Specifically, Hudson says that, "...in only 3 out of 187 assessments is evidence of the validity of facilitated communication supported and the one study involving the three successes has been criticized on methodological grounds". And Shane says that, "...for nearly 200 individual cases conducted by many research teams where controlled behavioural validation techniques were used, not one competent consumer of FC has emerged (Shane, 1993).

It is, quite simply, not true: people who use facilitation have passed tests, and reports of successful validations are in print.

There have certainly been a number of studies that have failed to find validation and there have been a number of positive studies. Looking only at published studies - journal articles and government reports - and looking only at studies that involved testing as opposed to qualitative reports of training programs, regardless of outcome, my current count is 4 positive studies (Calculator & Singer, 1992; IDRP, 1989; QDFSIA, 1993; Vazquez, 1993) in which 31 out of 37 people validated their ability to communicate with facilitation, and 5 negative studies (Eberlin et al, 1993; Hudson et al, 1993; Moore et al, 1993; Szempruch & Jacobson, 1993; Wheeler et al, 1993) in which 64 out of 64 failed to validate their ability to communicate with facilitation. At issue is not just the numbers who have passed or failed tests. Just as important are the issues of whether the study subjects had in fact been in a FCT program, whether the assessments used were valid, what the results signify, and the use that is made of them.

One continuing concern about the use of FCT in North America which I share with Howard Shane is the lack of interaction between FCT and AAC practitioners, and the tendency for FCT to be implemented by people with no training in either, as is evidenced by some of Shane's extraordinary stories of inappropriate FCT use. FCT is a subset of AAC. Correspondingly, the knowledge we have acquired over the last twenty or so years about the general application of AAC applies equally to FCT. Every reader of **Communicating Together** probably has favourite articles on AAC to which they refer regularly in lectures and discus-

sions. My most quoted articles include "Magic and the cost of communication competence" (Beukelman, 1991), "Communication aid today, competence tomorrow: Are we being realistic in our expectations?" (Haney, 1988), and "Gaining the most from AAC's growing years" (McNaughton, 1990). What these articles share is an acknowledgment that we still have a lot to learn about AAC intervention. They all recognise that AAC intervention does not provide a quick fix, and that most potential users need painstaking and lengthy training in order to acquire the skills necessary to use communication aids successfully: Haney suggests 5-6 years as the time frame needed to acquire basic communication competence.

For some reason there appears to be little recognition that this time frame also applies to people involved in FCT programs. FCT is being treated as 'magic' by many adherents and virtually all critics. The consumer shows unexpected competencies in one area, and is then assumed to have the same (or greater) levels of competence in other areas.

Let's take a hypothetical client called "Maria", aged 18, diagnosed as autistic and living in a segregated setting. Maria has a spoken vocabulary of less than 100 words, has been thought to have a mental age of 4, has been treated in many ways as a 4-year-old and in many ways behaves like a 4-year-old. She has always shown a great interest in books and has a large collection of Sesame Street books bought for her by her parents.

When facilitated, Maria demonstrates reading and spelling skills at around an 8-year-old level. Presuming for the sake of argument that this is an accurate assessment and that

Maria indeed has these skills, what do we know about her competencies, and what is it reasonable to expect her to be able to do? The answer has to be that we don't know. Maria has had an atypical life for a four or eight-year-old, much less an eighteen-year-old. She may be able to extend her literacy skills quite rapidly given appropriate input, but her social and interactive skills are not going to jump to an eight or eighteen-year-old level overnight.

Communication competence involves far more than being able to type out a sentence, however sophisticated a skill this may seem to be in relation to Maria's previous performance. Should Maria be given validation tests? When? How much training and experience should her facilitators have, both for everyday communication aid practice and for testing? If Maria fails a validation test, what does it mean and what should be done about it?

Answering all these questions goes well beyond the scope of this article, and I hope to address them in a future article on validation. In general my view is that one should factor barrier games and other 'message-passing' activities into Maria's communication program right from the start, not as do-or-die tests, but as part of regular therapy, documenting outcomes and working on areas of difficulty with both Maria and her communication partners. The first lesson of AAC, after all, is that it takes two to tango!

Maria may type for years before she provides the kind of validation which Shane and Hudson see as the only form of validation. Nonetheless, she may validate her participation in the program every day during that time by, for instance, improving her eye-hand co-ordination and concentration, by going to her communication aid when she wants something, or by positive changes in her behaviour and interactions. One validation, which would impress Maria's

parents, teachers and therapist but not quantitative researchers, occurs when Maria is distressed. Offered her aid, she spells out her need or her problem, and when this is addressed she calms down or shows pleasure.

Doug Biklen's article "Communication Unbound" was published in September, 1990. Very few people in the U.S. would have been involved in FCT programs before then - and it was a year or more after Biklen's article before FCT really took off. Correspondingly, most of those using facilitation for aid access now have been doing so for only a year or two. It wouldn't be surprising if they still lacked communication competence.

Shane says that some of the people who use FC are being manipulated and others are actually communicating but could do it without FCT. For a proportion of cases that's absolutely true. By the end of 1991, 31% of the students in the DEAL FCT program were able to type short sentences without facilitation (and this number in fact included some individuals who failed validation tests involving confrontational naming). The questions that Shane doesn't address are, "How long does achieving independent typing take?" "How do you develop the hand skills necessary?" and "What do you do about communication while you're working on someone's hand skills?" Independence can take years, and the best way we have yet found to encourage someone to communicate independently is to show them what communication can do by allowing them to communicate with assistance and to improve their hand function by giving them plenty of practice in pointing. That's what FCT aims to do. There's a continuum: some people *can* type independently straight away but have never previously been given the chance; some people can type after a short period of facilitation; some people take six or seven years to reach independence and some people are never going to make it. And of course, some people are independent in some

situations or with some equipment or with some people and not otherwise.

In response to Alan Hudson's comments regarding Carla, I *know* she can communicate through spelling because I and other people have seen her spelling single words or short phrases without any facilitation. Hudson doesn't comment on that at all. He simply says she can't communicate through spelling because she wasn't able to do the test he set her, and goes on to discuss the test. He objects to my statement that Carla's test was done with a new and untrained facilitator; however, the facilitator used in the testing had not been trained and the tapes made during the tests indicate that the facilitator either did not know the basic principles of facilitation or forgot them under pressure.

The limits of Hudson's attitude are perhaps shown most clearly in his account of Carla's attempt to back away from the allegations of sexual abuse she had made against her parents. On the last day of the Guardianship Board hearings Carla spelt out that she had lied about the allegations and that she wanted to withdraw them. Hudson regards this as impossible, and therefore as clear evidence that Carla had been manipulated throughout. Withdrawing her allegations was, in fact, sensible, and for Hudson to put it forward as impossible simply demonstrates his unwillingness to see Carla as a person.

§

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I've Only Got One Life, and I Don't Want to Spend It All Proving I Exist

ANNE McDONALD

These words do not exist. I do not exist. Howard Shane has said that facilitated communication is factitious, that no-one using facilitated communication has ever validated their communication, and consequently that the personalities presented to the world through facilitated communication do not exist. Howard Shane must be right; he is an AAC professional, and

“no group of professionals is more capable of identifying innate communicative and intellectual competence than the AAC professional . . .” (Shane, 1993).

For Howard Shane, writing off people who cannot talk is easy. For us to reply is hard, but you have to have gone for half of your life without speech to understand the full horror of what he is saying.

I have had athetoid cerebral palsy since birth and was once diagnosed as having profound intellectual impairment. I cannot talk, walk or feed myself, and I communicate by spelling with facilitation — that is, with someone supporting my arm while I point at letters on an alphabet board. I was placed in St. Nicholas Hospital, Melbourne, a state institution, at the age of three, and lived there without education or therapy for twelve years until Rosemary Crossley established communication with me in 1977, when I was sixteen.

When I was seventeen years old, a pediatrician was asked to assess my intelligence. The doctor refused to be told how I signalled “yes” and “no” — he said it might bias his assessment. He refused to see me in my posture chair, insisting that I be lain on my back. I couldn't sit up unsupported, and I couldn't use my

hands. He wanted me to reach for a plastic ring, and when I didn't he concluded that I was functioning at a less than 6/12 level. I was 17 — what would reaching for a plastic ring have proved? That I was a good baby? On his tests I could *never* have shown that I was intellectually normal.

Around the same time I was given, and passed, a series of validation tests. Several psychologists set me comprehension questions on written passages not seen by Rosemary Crossley. I answered the comprehension questions successfully, and the psychologists informed the hospital that I could read and spell. The hospital authorities ignored the positive reports of the psychologists then just as Howard Shane ignores them now.

I nearly starved to death on the floor of St. Nicholas. Many other children died there. Starving children with cerebral palsy to death is slower and nastier than gassing criminals, and is surely a cruel and unusual punishment even by American standards. Howard Shane doesn't care what happens to people unless the words they spell have been certified as correct by him and his colleagues.

In 1979, when I was eighteen, I fought the Health Commission in the Supreme Court of Victoria in order to win the right to leave (Crossley & McDonald, 1980). My parents and the hospital authorities denied my request on the grounds that the reality of my communication had not been established. The Health Commission psychiatrists attempted to conceal the favourable test results from the court but they came out anyway, the court accepted that my communication was my own, and I was allowed to go. If Howard Shane had his way I would never have left, because he would have tested me until I failed.

More Supreme Court proceedings were required to win the right to

manage my own financial affairs. During these proceedings I was asked in court to answer questions that Rosemary hadn't heard. Instead I spelt: “I don't like any suggestion that my communications aren't mine.”

They asked me again the following day. I spelt out another protest. On the third day, in response to a personal appeal from the Senior Master of the Supreme Court, I passed a message, with only minor changes; I was asked to spell two random words, “string” and “quince,” and I spelt two words — “string” and “quit”! That was enough for the court.

Unfortunately it does not seem to have been enough for Howard Shane.

While there may be specific instances in which validation of specific communication may be necessary, to suggest that people only be allowed to communicate if they've passed any test any skeptic wants to push on them is not only impractical but a violation of civil liberties. Communication is not easy for people like myself, and there is nothing to gain from regulating my right to talk to whoever is prepared to take the time to listen.

How can Howard Shane say that he is trying to help people with disabilities when he tries to push me out of the human race? First I was institutionalized as an affront to humanity, then evidence that I was not intellectually impaired was concealed, and now Howard Shane is saying that I cannot communicate. If this is what my “friends” do, what can I expect from the community at large?

In fact professionals are not my friends. I challenge them by being living proof that their tests and judgements are fallible. I am not the beneficiary of the work of professionals — I am their victim. I can't get away from my disability, but I should be able to escape being cast as a permanent patient.

Last year I gave a paper at the TASH conference in San Francisco on the right to communicate. It concluded with these paragraphs:

"For people without speech, talking is often dependent on the generosity of others, either in providing interpretation or facilitation or in giving up time to listen. While this is inevitable, there needs to be an irreducible right to make your opinions known on issues concerning your future well-being. At the moment social conversation and medical consent are equal in the sight of the law, both depending on the accidental availability of communication partners with the necessary skills and commitment. There is no right to be heard. There is no right to an interpreter. There is no obligation to listen.

While social interactions will always be dependent on the politeness and tolerance of individuals, it should be possible to legislate for a right to communicate in formal situations such as courts, hospitals and schools. Without such legally enforceable rights, people without speech will be at the mercy of decision-makers who can arbitrarily decide to disallow communication.

Communication falls into the same category as food, drink and shelter — it is essential for life. Without it life becomes worthless.

TASH passed a resolution recognizing the right to communicate. ISAAC should do likewise.

A Response to Anne McDonald

HOWARD SHANE

In light of my conclusion in the paper, *FC: Factitious or Facilitated Communication*, it would be illogical to direct a response to Anne McDonald. The controversy surrounding Facilitated

Communication is about a controversial technique and not whether people with disabilities have value. Let the proponents of FC defend the techniques through sound research rather than personal assaults. My argument is not with people with disabilities, but rather with a procedure that potentially violates an individual's civil rights. Be clear. I do not dismiss Anne McDonald as a human being undeserving of dignity and respect. So, whether Anne McDonald actually penned that response or not is irrelevant to whether I accept her as a person. I accept her like anyone regardless of her level of communication ability or intellect.

In Defence of Howard Shane - 1

RUTH SIENKIEWIECZ-MERCER

I have cerebral palsy and severe physical disabilities due to years of neglect. I lived at Belchertown State School for sixteen years. I saw a letter that attacked Howard Shane and wanted to reply. I feel that I can best do this by presenting excerpts from my book *I Raise My Eyes To Say Yes*. First of all, the following details what doctors and other health professionals had said about me:

My intake evaluation labeled me an imbecile, and thus determined how the nurses and attendants were to treat me for the next few years. Since everyone assumed that I couldn't understand what was going on around me, they ignored any and all evidence that I could present to the contrary. I cannot view this label as an understandable mistake, because it took nearly ten years before it was officially changed (p. 39)

As important and welcome as these changes were, they were insignificant compared to one other development at this time: I started school.

Our teacher was Howard Shane, a recent college graduate who was new to the state school. Although some of the verbal residents at the Infirmary, like Carol Muse, had been receiving basic education for some time, Howard was the first person at Belchertown to teach nonverbal residents. Our class started in December 1969 in one of the small rooms off the hallway between the wards. There were 58 other girls from the class, most of them from Ward 3. Howard Shane was faced with an unusual group of students, but after that bizarre first day, we settled down to business. He worked with us on both a group and an individual basis, starting on the fundamentals, the alphabet, rudimentary spelling and simple arithmetic.

Fortunately my mind had not atrophied from inactivity like my arms and legs. From the outset I was thrilled about being in a classroom again, especially with Howard. He never got hung up on our physical infirmities in relating to us and teaching us. Instead, he asked questions and actually listened to our answers, reading our faces and our eyes when necessary, or taking cues from the sounds we made. Howard very quickly came to understand the particular nonverbal language that each one of us nontalkers used. He was gentle and patient, and never patronized any of us.

Howard was also our zealous advocate. He regularly challenged the Infirmary and State School administrators - but not the direct-care staff - about our overall treatment as well as our educational needs. He sharply criticized the lack of activities and social interaction for the residents of the infirmary.

I never doubted that I was capable of benefiting from a complete education, and Howard felt this way about me too. Moreover, he believed that with professional training and hard work, I could communicate my thoughts to others well beyond my yes-or-no facial expressions.

Although I wholeheartedly agreed with Howard's progressive ideas, much of the staff at the infirmary and nearly all of the administrators at the State School did not. Our class met with Howard regularly until the Summer of 1976, when he returned to college to work on an advanced degree in speech disorders. I'm sure that when he left that Summer, many of the people in charge at Belchertown breathed a sigh of relief (p. 148-150).

In Defence of Howard Shane - 2

RICK HOYT

I have cerebral palsy and communicate independently through the use of augmentative communication technology. I am writing this letter to respond to a letter I saw entitled "*I've Only got one life, and I don't want to spend it all proving I exist*". The author wrote that Howard Shane is a set-back to people from institutions. If this person took the time to do some checking into his background, she would have found out that Howard had worked at the Belchertown State School for the retarded. His employment had been terminated as he was seen as a trouble maker by the administration. In fact, Howard had helped to leak information about the poor conditions at Belchertown to the press, leading to an investigation of the institution. During graduate school Howard also worked as a group home parent for five children who were mentally retarded and many were released from an institution in Syracuse, New York.

The reason why Howard would like to test this woman is, he just wants to know whether or not the woman's system of communication is really suited for her needs. I'm amazed that this woman would attack Howard, especially when they have never had a face to face meeting.

My understanding of the controversy is that Howard is questioning the method that this woman communicates with. He would never form an opinion of someone without meeting the person or having thoroughly studied the form of communication. Howard did not attack this young lady personally. He only wishes to validate the method she uses to communicate.

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The articles about Facilitated Communication appearing in this issue, along with the *Perspective* by Howard Shane which originally appeared in **Communicating Together**, June, 1993, and a composite list of the publications referenced in all the articles, is available through the **Sharing to Learn Informal Publication Series**. The articles and reference list appear as a *Postscript* in *Annotated References and Additional Readings Related to Facilitated Communication, 2nd. Edition*. The price per copy is \$20.00 Canadian. Order from: Sharing to Learn, P.O. Box 986, Thornhill, Ontario, Canada L3T 4A5; Phone 905-771-1491; Fax 905-771-7153.



Holiday Greetings from all of us at Communicating Together!

*Sara-Jo McNaughton, Colleen McGaffey, Shirley McNaughton, Rob Haaf, Suzanne Clancy,
Paul Marshall, Geb Verburg, (back); Peter Lindsay, Nola Millin, Ruth and Kari Harrington (front).*

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